

1970-2010

Honoring our Past, Shaping our Future

**A Report from NACDD upon the 40th Anniversary of the Creation
of Councils on Developmental Disabilities**



National Association of Councils on Developmental Disabilities (NACDD)

NACDD serves as the national voice of State and Territorial Councils on Developmental Disabilities. We support Councils in implementing the Developmental Disabilities Assistance and Bill of Rights Act and promoting the interests and rights of people with developmental disabilities and their families. www.nacdd.org

Executive Summary

2010 is a milestone year for people with developmental disabilities and those who advocate with and for them. As many know, it marks the 20th anniversary of the passage of the landmark Americans with Disabilities Act. Less known is that 2010 is also the anniversary of the inclusion of Councils on Developmental Disabilities as part of the reauthorization of the Developmental Disabilities and Bill of Rights Act (DD Act) of 1970. The creation of Councils paved the way for further innovation on key issues including health, employment, education, housing and transportation, and for further empowerment of people with developmental disabilities and their families.

Today, over 5 million Americans have a developmental disability: a severe, chronic disability that begins any time from birth through age 21 and is expected to last for a lifetime. While not always visible, these disabilities can result in serious limitations in everyday activities of life, including self-care, communication, learning, mobility, or being able to work or live independently. The term “developmental disability” includes a range of conditions, including but not limited to autism, cerebral palsy and intellectual disabilities.

Thus the Councils on Developmental Disabilities (DD Councils), by their nature, bring different constituencies together for a shared purpose: to foster and build more inclusive communities that give everyone opportunities to reach their fullest potential.

The Developmental Disabilities Assistance and Bill of Rights Act in 1970 created State and Territorial Councils on Developmental Disabilities to identify the most pressing needs of people with developmental disabilities and to ensure that people with developmental disabilities and their families receive the services and supports they need, and participate in the planning and designing of those services in a manner that upholds the dignity and value of people with developmental disabilities. Councils have been involved in nearly every aspect of the development of our nation’s current service delivery system for persons with developmental disabilities, and consistently work to promote systems change that will eliminate inequities in areas such as employment, education, and access to health care.

Since their creation in 1970, the role and mission of DD Councils has progressively changed as our knowledge and commitment to persons with developmental disabilities has grown. Our country has experienced a major social and cultural shift in how society views people with disabilities. In the 1970s, Councils were at the forefront of developing infant intervention and early childhood programs; in the 1980s, Councils piloted supported employment programs that were eventually incorporated into vocational rehabilitation and DD service systems; in the 1990s, Councils were active in developing personal assistant services, family support and home ownership programs, and other services and supports; and in more recent years, Councils have focused on developing the critical relationship between employment, housing, and transportation.

While we are proud of the work and accomplishments of DD Councils, we also fully understand and appreciate the enormous challenges that remain for people with developmental disabilities and their families. Expectations of people with developmental disabilities remain low, as evidenced by the high unemployment rate of people with developmental disabilities. Too many people with developmental disabilities live in segregated settings, isolated from the broader community. Youth with developmental disabilities typically have few if any viable employment options when they leave school. We must redouble our efforts to advance effective transition from school to work, to increase access to true community-based housing and employment training, improve transportation options and ultimately create inclusive communities where everyone, regardless of disability status, is able to realize their full potential.

People with Developmental Disabilities

Over 5 million Americans are estimated to have developmental disabilities (DD.)¹ As the DD Act states, “Disability is a natural part of the human experience...” Indeed, developmental disabilities can occur in any family, no matter their ethnic, social, economic or religious background. Without coordinated services and supports, persons with developmental disabilities are often unemployed, and disproportionately live at or below the federal poverty level.

As defined in the Developmental Disabilities Assistance and Bill of Rights Act of 2000, a developmental disability (DD) is a severe, chronic disability that begins any time from birth through age 21 and is expected to last for a lifetime. Developmental disabilities may be cognitive, physical, or a combination of both. While not always visible, these disabilities can result in serious limitations in everyday activities of life, including self-care, communication, learning, mobility, or being able to work or live independently. Such disabilities are almost sure to result in a lifetime of dependence on publicly funded services, *unless* families receive sufficient support, children receive appropriate education, and adults receive appropriate services that enable them to live and work in their communities.

Councils on Developmental Disabilities

Councils on Developmental Disabilities are located in every State and Territory. They represent Federal-State partnerships, as well as public-private partnerships, in developing futures for and with people with developmental disabilities and their families. Councils are made up of volunteers who are appointed by Governors. More than 60% of Council members must be people with developmental disabilities or family members. In this way, the recipients of services and supports of the service system direct the Council’s activities.

Councils are charged by Federal law to identify the most pressing issues confronting people with developmental disabilities in their State or Territory and to ensure that people with developmental disabilities and their families receive the services and supports they need and participate in the planning and designing of those services in a manner that upholds the human and civil value of people with developmental disabilities.

Councils work to promote the independence and productivity of people with developmental disabilities and promote systems change that will eliminate obvious inequities in areas such as employment, education, and access to healthcare. Councils work to create a community where people with developmental disabilities are naturally included and where they can enjoy the same civil liberties and quality of life as everyone else.

The Evolution of Developmental Disabilities Policy

The 1970s

In 1970 a total of 181,404 persons with intellectual and other forms of developmental disabilities (I/DD) lived in nearly 250 state-operated institutions across the states. An estimated 13,535 persons with I/DD resided in settings for six or fewer persons. In 1971, Congress enacted Pub. L. 92-223, authorizing “intermediate care facilities” which would soon be the mode of Medicaid reimbursement for I/DD institutions. The only federal reimbursement for community I/DD services in 1970 was an estimated \$43 million in social services funding.

¹ <http://www.cdc.gov/niosh/topics/wdd/>

In 1970, Congress passed the Developmental Disabilities Services and Facilities Construction Amendments which mandated that states develop DD programs and pay closer attention to the wants and needs of persons with developmental disabilities and their families. The Act also mandated that Developmental Disabilities Councils be established in each state to assist in the process, and officially created and defined the term “developmental disability,” then defined as “a disability attributable to mental retardation, cerebral palsy, epilepsy, or another neurological condition.”

Indeed, the 1970s was a milestone decade for the DD movement, especially in terms of litigation, legislation, and the protection of civil rights. This and other pieces of legislation, spurred by grassroots movements, have greatly improved the lives and opportunities of individuals with a developmental disability. The provision and breadth of state and community services have greatly changed over time, as our knowledge and commitment to this population has grown.

During this decade, a “Parents’ Movement” grew, alongside the self-advocacy movement, and advocates worked to expand community services and ensure equal access to education and employment. Parents also increasingly turned to the courts, successfully filing lawsuits to enforce the civil and legal rights of their children. Parents, other family members and most importantly people with developmental disabilities themselves organized to change and enforce laws and to challenge public attitudes about disabilities. They addressed issues of concern in housing, education, employment, and overall community involvement. The result was a more earnest effort on behalf of states and communities to provide necessary services to the disabled that better enabled them to become full, active members of their communities.

In 1975, Congress passed The Developmental Disabilities Assistance and Bill of Rights Act, thereby comprehensively revamping the Developmental Disabilities Services and Facilities Construction Amendments of 1970. Among the many changes mandated was the expansion of the definition of developmental disabilities to include autism and dyslexia. Both the Act and the definition continued to be amended periodically until 2000.

Also passed in 1975, The Education for All Handicapped Children Act mandated states to provide education to disabled children in a way that addressed their needs by requiring (1) the development of individualized education programs (IEPs); (2) the identification of specific goals and objectives; and (3) the development of specific descriptions of special education. Since its passage, the Act has been amended to provide additional guidelines and requirements and was re-titled, The Individuals with Disabilities Education Act (IDEA).

The 1980s

By 1980, the average daily resident population of state-operated I/DD institutions had dropped to 132,690, but federal ICF/MR funding had increased to \$1.5 billion. In 1981, Congress authorized the Home and Community Based Services (HCBS) Waiver (Pub. L. 97-35). In 1980, an estimated 28,000 people with intellectual and other forms of developmental disabilities lived in six person or fewer settings.

The 1980s saw the passage of additional legislation: the 1982 Tax Equity and Fiscal Responsibility Act (TEFRA), the 1986 Amendments to the Rehabilitation Act, and the 1986 Employment Opportunities for Disabled Americans Act. This legislative trend culminated with the 1990 passage of the landmark Americans with Disabilities Act (ADA), which affirmed the civil rights of persons with disabilities and prohibited discrimination in the areas of employment, public services and accommodations, and telecommunications. In the 1980s, advocates continued to use class action lawsuits to challenge conditions in state-operated institutions.

The 1990s

By 1990, the state-operated institutional census was 84,818, smaller than the number of persons with I/DD living in six person or fewer settings: 101,776. More and more states were providing supports to families and individuals. In 1990, 113,807 families were supported and there were 13,357 supported living participants and 38,919 supported employment workers with I/DD. Federal Medicaid reimbursement totaled \$4.1 billion compared to \$0.5 billion for the Home and Community Based Service (HCBS) Waiver.

Class action litigation emerged to compel states to expand services to persons with I/DD on waiting lists, meet Olmstead requirements related to community alternatives to institutions, and provide Medicaid services to which people were entitled.

In addition to the closing of many large state institutions for people with developmental disabilities and the construction of smaller community living facilities increased, other reforms included several initiatives that increased support to people with developmental disabilities in the purchasing of homes, including the Administration on Developmental Disabilities (ADD) funding of Home of Your Own Demonstration Projects in several states, and the development of the National Home of Your Own Alliance.

The 21st Century

In the year 2000, 47,397 persons with I/DD resided in state-operated institutions, less than one-fifth the 269,131 persons in group homes, foster homes, apartments, and supported living arrangements for six or fewer persons. Families supported totaled 319,591, supported living participants totaled 107,931, and there were 105,906 supported employment workers with I/DD. Federal HCBS Waiver reimbursement totaled \$5.57 billion in 2000, just below Medicaid ICF/MR reimbursement of \$5.61 billion.

In 2001, the federal government developed the New Freedom Initiative with the intention to “remove barriers to community living for people of all ages with disabilities and long-term illnesses.”

In 2009, the nation’s institutional I/DD census was 33,795, and 439,950 persons lived in settings for six or fewer persons. Families supported totaled 490,319, supported living participants totaled 227,901, and there were 103,746 supported employment workers (a slight decline from the level nearly 10 years earlier). Federal HCBS Waiver spending totaled \$15.4 billion, two times the federal ICF/MR spending of \$7.7 billion.

By 2009, 142 state-operated institutions had closed; fewer than 200 facilities remained and 12 jurisdictions (Alaska, District of Columbia, Hawaii, Indiana, Maine, Minnesota, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, and West Virginia) had closed all state-operated institutions for persons with I/DD. The states spent \$53.5 billion on I/DD residential and community services; 84% of the total was committed to community services and supports, with the remaining 16% supported public and private institutions for 16 or more persons.

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act)

The DD Act is the law supporting, enhancing, and protecting the lives of people with developmental disabilities and their families. The DD Act provides federal financial assistance to states and public and nonprofit agencies to support community-based delivery of services to persons with developmental disabilities to create and enhance opportunities for independence, productivity, and self-determination.

DD Act funds support initiatives in civil rights protections, education and early intervention, childcare, health, employment, housing, transportation, recreation, family support, and other services. The key DD Act components are:

1. State Councils on Developmental Disabilities (DD Councils): Councils are required by Federal law to identify the most pressing needs of people with developmental disabilities in their State or Territory and to ensure that people with developmental disabilities and their families receive the services and supports they need; Councils work to develop innovative and effective services and supports to meet these needs.
2. Protection and Advocacy (P&A) systems: P&As are required to pursue legal, administrative, and other appropriate remedies under all applicable federal and state laws to protect and advocate for the rights of individuals with developmental disabilities by guarding against abuse; advocating for basic rights; and ensuring accountability in health care, education, employment, housing, transportation, and within the juvenile and criminal justice systems.
3. University Centers for Excellence in Developmental Disabilities (UCEDDs): UCEDDs are required to provide interdisciplinary training to students and professionals, engage in cutting-edge research, and provide technical assistance, and direct services and supports to people with disabilities of all ages and their families.
4. Projects of National Significance (PNS): PNS is a discretionary program that supports local implementation of practical solutions and provides results and information for possible national replication. PNS also supports technical assistance; research regarding emerging disability issues; conferences and special meetings; and the development of Federal and state policy.
5. Family Support Programs: The Family Support Program promotes and strengthens the implementation of comprehensive State systems for in-home supports for families caring for individuals with disabilities. Family support services are effective in reducing the costs associated with life-long disability, and in preventing expensive out-of-home placements. (The Family Support Program Title in the DD Act has not been funded; family support initiatives have received some funding through the Act’s Programs of National Significance.)

How the DD Act has Transformed Councils over Time

- 1970:** Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and Developmental Disabilities Services and Facilities Construction Act of 1970 (P.L. 91-517)
- State Councils are created and charged to identify the most pressing needs of people with developmental disabilities in their State or Territory and to ensure that people with developmental disabilities and their families receive the services and supports they need and participate in the planning and designing of those services in a manner that upholds the dignity and value of people with developmental disabilities. This core mission of planning, coordinating, and developing new services and programs has not changed over time.
- 1975-1978:** Developmental Disabilities Assistance and Bill of Rights Act Reauthorization of 1975 (P.L. 94-103) and Developmental Disabilities Amendments of 1978 (P.L. 95-602)
- State Councils are charged with the more active role of advocacy and are no longer considered to be merely “advisory.” State Councils are charged with preparing State plans on deinstitutionalization

to facilitate persons with developmental disabilities’ transition from institutions to homes and communities, while simultaneously improving the quality of institutional care. Councils are also given the responsibility to provide services to persons whose needs were not satisfied under the Education for All Handicapped Children Act (P.L. 94-142) or the Rehabilitation Act of 1973.

Also during this time, the definition of “developmental disability” in the DD Act is modified to focus less on listing specific disabilities and more on the lifelong needs of persons with developmental disabilities; State Council consumer representation requirement is raised to 50%; and the original 16 basic service categories in earlier legislation are eliminated and replaced by the “priority areas” of case management, child development, alternative community living arrangements, and non-vocational, social development services.

- 1984-1987:** Developmental Disability Act of 1984 (P.L. 98-527) and Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 (P.L. 100-146)

It is made clear that State Councils are required to provide service activities, not direct services themselves. In a similar vein, “employment-related activities” becomes a mandated priority, and State Councils place a greater emphasis on providing information, training, and support for persons with developmental disabilities in employment. In “People First” language, for the first time, “supported employment” and the values of Independence, Productivity, and Integration were federally defined.

The reforms of 1987 further expanded the role of the State Councils by mandating them to focus on systemic change. State Councils were thus strengthened as more independent agencies, allowing for greater flexibility in addressing the unique needs of persons with developmental disabilities in their States. Given that the bill was more focused on the capabilities, competencies, preferences, and needs of persons with developmental disabilities via amendment, State Councils changed their missions and activities accordingly.

- 1990-1994:** Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1990 (P.L. 100-496) and Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994 (P.L. 103-230)

The independence of State Councils was strengthened, Councils were explicitly permitted to engage in systemic change, capacity building, and advocacy activities for individuals with developmental and other disabilities. In addition, “Projects of National Significance” are established to investigate the expansion of Council activities to individuals with severe disabilities other than developmental disabilities. Furthermore, the role of a Designated State Agency (DSA) is explicitly defined to provide support services “as requested by and negotiated with the Council,” and the amendments required the DSA to enter into a memorandum of understanding with the Council if requested.

- 2000-2010:** Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402)

Councils are required to: 1) report on waiting lists in each state and to establish a goal and be involved with self-advocacy organizations and leadership training opportunities; 2) be made up of at least 60% individuals with developmental disabilities or family members, and have a representative of the Medicaid Title V agency on the Council; 3) include information about consumer satisfaction with Council supported activities in their annual reports; and 4) conform with new revised requirements for State Plans.

Additionally, “areas of emphasis” (instead of “priority areas”) are added, as well as a formal definition of, and emphasis on, self-determination. Areas of emphasis are: quality assurance, education and early intervention, child-care, health, employment, housing, transportation, recreation, and other services available or offered to people in a community which affect their quality of work.

DD Councils Today

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) of 2000 states that the purpose of State Councils is to “engage in advocacy, capacity building, and systemic change activities that are consistent with the purpose of the DD Act and; contribute to a coordinated, consumer and family-centered, consumer and family-directed, comprehensive system of community services, individualized supports and other forms of assistance that enable individuals with developmental disabilities to exercise self-determination, be independent, be productive and be integrated and included in all facets of community life.”

State Plans: Each Council develops a State Plan, identifying specific five-year goals for their State. Councils implement their State plans by conducting activities such as: outreach, training, technical assistance, supporting and educating communities, interagency collaboration and coordination, barrier elimination, systems design and redesign, coalition development and citizen participation, informing policymakers, and demonstration of new approaches to services and supports.

Areas of Emphasis: Areas of emphasis in which Councils must work are related to activities in quality assurance, education and early intervention, child-care, health, employment, housing, transportation, recreation, and other services available or offered to people in a community which affect their quality of work.

Goals: Councils work toward public policies that promote the following goals for people with developmental disabilities:

- Self Determination – Activities that result in individuals with developmental disabilities having the ability and opportunity to communicate and make personal decisions, exercise control over the type and intensity of supports and services they receive, the authority to control resources, opportunities to participate in and contribute to their communities, and support to advocate for themselves and others.
- Inclusion – Acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities.
- Integration – Exercise of the equal right of individuals with developmental disabilities to access and use the same community resources as are available to and used by other individuals.

Federal Policy: Where We Stand Now

The Administration

At its outset, the Obama Administration issued a series of goals and objectives to benefit people with developmental and other disabilities:

- Strengthen access to, and improving the quality of, health care
- Promote access to community living services
- Protect civil rights via the Americans with Disabilities Act (ADA)
- Expand educational opportunities
- Increase access to employment

The Administration included provisions to benefit people with developmental and other disabilities in two of its major legislative priorities. The American Recovery and Reinvestment Act (ARRA) of 2009, included \$500 million for the Social Security Administration to increase its efficiency in processing disability applications; \$12.2 billion for the Individuals with Disabilities Education Act (IDEA); \$87 billion for State Medicaid programs; and \$500 million for vocational rehabilitation services.

The enactment of the health care reform bill, The Patient Protection and Affordable Care Act, is perhaps the biggest legislative leap forward for people with developmental disabilities and their families since the passage of the ADA. In addition to insurance reforms that prohibit discrimination based on preexisting conditions, an end to lifetime caps in coverage, and other provisions, the health care Act includes long terms services and supports insurance (CLASS Act provisions) that will benefit people with developmental disabilities and their families.

President Obama has appointed an advisor on disability issues who sits on the White House Domestic Policy Council, and an outstanding team of leaders at key agencies including the Office on Disability, the Administration on Developmental Disabilities (ADD), the Office on Disability Employment Policy (ODEP), and the Rehabilitations Services Administration (RSA.) Furthermore, the President has instructed officials across his Administration to consider and include the needs of people with disabilities in all aspects of the federal government’s work.

The Congress

In addition to passing the health care reform bill and the stimulus package, Congress extended the Federal Medicaid Assistance Percentage (FMAP) which is crucial to prevent cuts in essential services and supports for people with developmental disabilities

A number of bills have been introduced that address a range of issues of concern to NACDD and people with developmental disabilities and their families, including:

- Achieving a Better Life Experience (ABLE) Act of 2009 (H.R.1205 and S. 493): Amends the Internal Revenue Code to establish tax-exempt ABLE accounts for persons with a disability to pay for certain expenses such as education, employment support, and medical care.
- Frank Melville Supportive Housing Investment Act of 2009 (H.R. 1675): Creates supportive housing through Section 811 vouchers program for people with the most significant and long term disabilities who can benefit from community-based services.

- Keeping All Students Safe Act (H.R. 4247) passed the House, March 2009; The Senate version (S 2860) awaits Committee action as of publication date: Outlines federal minimum standards to limit restraint and seclusion in schools.
- Rosa’s Law (S 2781) passed the Senate in August, 2010 and awaits House consideration: Changes references in federal law from “mental retardation” to “intellectual disability.”

Furthermore, Congress is expected to address the reauthorization of a number of Acts in 2011 that impact people with developmental disabilities, including:

- Elementary and Secondary Education Act
- Developmental Disabilities Act
- Combating Autism Act
- Vocational Rehabilitation Act
- Workforce Investment Act

NACDD will continue to work through coalitions and independently to inform Congress and the Administration on these and other pieces of legislation, and especially to share Councils’ expertise and perspectives on the issues of most importance to people with developmental disabilities.

The Ongoing Need for Councils on Developmental Disabilities

Before the passage of the Developmental Disabilities Act in 1970, families received almost no help, children often could not attend school, and many people were sent to State institutions for life. During the past 40 years, Councils have helped to bring about some remarkable changes:

- Today there is a societal expectation that children with developmental disabilities will grow up in families, and that families will receive needed supports.
- The total number of people with developmental disabilities in State institutions has dropped significantly.
- Increasingly, infants and toddlers are receiving needed and timely services to help them get the earliest possible start on learning and development.
- Children with developmental disabilities are going to school with children from their own neighborhoods.
- Increasingly, young adults with developmental disabilities learn to work in real job settings for competitive wages, and their expectation is to participate in the workforce.
- More adults with developmental disabilities have jobs and live in homes of their choice.

While we celebrate this progress, we acknowledge the challenges that remain:

- Adults with developmental disabilities continue to experience the highest unemployment rate of any group of Americans
- Many people with developmental disabilities and their families remain on long waiting lists for services and housing
- Thousands of people with developmental disabilities remain in institutional settings
- Many people with developmental disabilities remain isolated from the everyday experiences of friendship and participation on community life

Our Priorities

Today, Councils on Developmental Disabilities work toward public policies that promote several overarching goals for people with developmental disabilities: Self Determination,³ Inclusion,⁴ and Integration,⁵ and focus on eight major areas of emphasis: quality assurance, education and early intervention, child-care, health, employment, housing, transportation, recreation, and other services available or offered to people in a community which affect their quality of work. NACDD’s positions on these areas of emphasis are below. To learn more about the work of specific Councils in each of these areas, visit their websites, which are listed in the Appendix; links to Councils’ sites are also available at www.nacdd.org.

Quality Assurance

Quality Assurance is a confirmation of whether or not products or services meet or exceed customer expectations. Quality assurance involves advocacy, capacity building, and systemic change activities resulting in improved choice in consumer and family-centered services for individuals with developmental disabilities. Quality assurance activities include interagency coordination and collection of data resulting in improved services, supports, and other assistance.

NACDD believes individuals with developmental disabilities must define quality. All service systems, such as education, employment, health, housing, child care, recreation, transportation and any other system that impacts persons with developmental disabilities should actively engage these individuals and their families in quality assurance. This included identifying problems and making improvements that enhance the quality of life for people with developmental disabilities.

Councils focus on improving consumer and family-centered quality assurance and consumer protections by conducting training in leadership, self-advocacy, and self-determination and working closely with service providers, advocacy organizations and government agencies. An example of this work is Partners in Policymaking, a leadership and advocacy training program developed by the Minnesota Council for adults with disabilities and their families. A number of Councils have invested in this program that educates and trains participants to be more effective advocates on state and federal issues including housing, employment and education.

Community Support

Over 5 million children and adults in the United States have developmental disabilities, and most of them live at home with families. However, they too often receive few if any services and face long waiting lists for needed supports. NACDD believes people with developmental disabilities should have access to the services, supports and accommodations needed to live in the setting of their choice and to participate fully in community life. Children with developmental disabilities should receive the services and supports needed to live in the most integrated settings. Individualized community options should be rapidly expanded where needed to all individuals in institutional settings to return to the community.

Councils advance community support in a number of ways, including by training people with developmental disabilities to understand and utilize self-directed services, supporting and strengthening direct support workers, and analyzing existing state services to determine which are most effective.

³ Self-Determination defined as activities that result in individuals with developmental disabilities having the ability and opportunity to communicate and make personal decisions, exercise control over the type and intensity of supports and services they receive, the authority to control resources, opportunities to participate in and contribute to their communities, and support to advocate for themselves and others.

⁴ Inclusion defined as the acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities.

⁵ Integration defined as exercise of the equal right of individuals with developmental disabilities to access and use the same community resources as are available to and used by other individuals.

Education and Early Intervention

Councils understand that public education is the mechanism by which this nation prepares all students to pursue the benefits of freedom and to exercise their rights and responsibilities as citizens. Education is a lifelong process.

NACDD believes students with developmental disabilities should receive a quality, free and appropriate public education that is inclusive, fully funded, with the needed individualized supports and related services (adaptive, assistive technology, modification and supplementary aides) to ensure educational success. Students should be provided individualized appropriate instruction; research based positive behavior supports in the least restrictive setting by qualified teachers, administrators and other service providers.

Among the ways that Councils strengthen education and early intervention are by informing families about their educational option and rights, surveying educators and helping to prepare them to support students with disabilities in their classrooms, and training students with disabilities on leadership, community service and other areas.

Child Care

Families of children with disabilities often have difficulty finding high quality child care, due to the inability or unwillingness of many child care providers to accept children with disabilities, transportation and other logistical problems, difficulties with coordinating early intervention and child care services, and the scarcity of appropriately trained caregivers.

NACDD believes child care services for families of children with disabilities should build on the strengths of the child and family, address their needs, be culturally competent, and be delivered through research-based practices. Child care services, before and after school care programs should occur in natural settings based on inclusive models of care with properly trained professionals. These services should be affordable, safe, and enhance the overall well-being and development of children with developmental disabilities.

Councils work towards quality inclusive child care in various ways, including by building capacity and providing financial support to model inclusive child care programs.

Health Care

Individuals with developmental disabilities are more likely to experience early death, chronic conditions, and preventable health conditions, compared to persons without disabilities. Even with access to care, people with developmental disabilities often have difficulty recognizing and communicating their own health care needs. Moreover there is a significant shortage of qualified, trained health care professionals who are prepared and willing to treat them.

NACDD believes comprehensive health care must provide affordable health, dental and vision coverage, improved quality, and better cost control, while addressing the significant health and health care disparities faced by individuals with developmental disabilities. In addition to improving access to quality medical care for persons with developmental disabilities, the health care system must improve the way our nation provides long term services and supports related to health care (such as assistance and supervision with activities of dialing living, taking medication and preparing meals.)

NACDD applauds the passage of health care reform legislation and urges policymakers to strengthen, not hinder, reform. NACDD especially supports the inclusion of CLASS Act provisions that begin to address the long term services and supports crisis.

Councils are engaged in improving access to health care and improving the health and wellness of people with developmental disabilities, including by training health care providers on best practices in treating persons with developmental disabilities and educating people with developmental disabilities and their families to enable them to seek and receive health care.

Employment

Working age people with developmental and other disabilities are among the most unemployed and underemployed segments of our society. Too often, unemployment is accepted as an inevitable result of living with a significant developmental disability. Employment is the avenue to independence and increased socialization for individuals with developmental disabilities.

NACDD believes individuals with developmental disabilities should have access to the resources and supports necessary to gain and maintain meaningful community-based employment.

Councils are working hard to address the employment crisis of people with developmental disabilities, including by leading state level initiatives to advance “Employment First” which fundamentally changes expectations and makes employment the expected outcome, funding self employment projects, and providing transition training for youth with disabilities who are graduating from high school or college.

Housing

Across the nation, people with developmental disabilities face a severe crisis in the availability of decent, safe, affordable and accessible housing. Many individuals with developmental disabilities still live in large congregate facilities or other institutions.

NACDD believes that citizens with developmental disabilities should live in inclusive, safe, accessible and affordable communities of their choice, with people they choose to live with and be provided with the needed individualized supports and accommodations.

Some of the ways that Councils address housing issues are by working with state and local agencies to develop affordable accessible housing, educating people with developmental disabilities on housing options including home ownership, and promoting integrated, community-based housing as the preferred outcome for people with developmental disabilities.

Transportation

Within our society, freedom of movement is a fundamental right. However, it remains a largely unfulfilled promise for citizens with disabilities. Millions of Americans with developmental disabilities have difficulties obtaining transportation that serves as a vital lifeline to employment, education, health and community life.

NACDD believes all publicly funded and/or regulated transportation services systems must be: seamlessly coordinated among all modes of transportation; expanded in suburban, urban, rural and incorporated areas to connect places people live with places they work, shop, socialize, worship, attend school, access health care, etc.; incorporated with mobility management and training services for individuals with disabilities; designed to appropriately address insurance and liability of vehicles and operators who service in a coordinated transportation environment, including non-profit providers); based on principles of universal design; supported by stable and adequate funding; and fully accessible to all people with disabilities.

Councils work to increase accessible transportation in various ways, including by training people with developmental disabilities on their rights under the ADA, funding projects that provide affordable, accessible transportation at the community level, and advocating at the state level for improvements to transportation systems.

Recreation

The quantity and quality of available opportunities for people with developmental disabilities to learn leisure skills, develop leisure interest and participate in inclusive community recreational opportunities continues to be fairly low.

NACDD believes individuals with developmental disabilities should be afforded the same opportunities as those without disabilities to develop leisure interests and skills through inclusion in community opportunities afforded all children and adults for leisure education and recreation participation.

Some of the ways that Councils address recreation are by working to ensure that recreation facilities, including parks and playgrounds, are accessible and training recreation providers and users on best practices to ensure that people with developmental disabilities are included in recreational programs.

Shaping our Future: Working Towards Full Inclusion

Forty years after the creation of DD Councils, America is confronting one of the worst economic downturns in its history. As unemployment and poverty levels rise, it is essential that we as a nation not forget people with developmental disabilities as we work towards economic recovery. Now is the time to engage the public and private sectors to find solutions to the employment crisis, and to support programs and policies that aren’t hand outs but are “hand ups” for people with developmental disabilities. Persons with developmental disabilities deserve to be full participants in community life. We can make significant progress towards this goal by:

Expanding opportunities for meaningful, integrated employment and providing the necessary resources to assist in successful transitions from school to work; Making “Employment First” the norm across the country

Working age people with disabilities face an unemployment rate of 39.3%, and 25.3% lived below the federal poverty level. People with developmental disabilities face even high unemployment rates, and as noted earlier in this report, unemployment is too often (and wrongly) accepted as the inevitable result of living with a significant physical, cognitive or emotional disability. Segregated sheltered workshops or day programs are often the anticipated endpoint after an individual leaves school. There is often no expectation, and therefore no preparation, for individuals with developmental disabilities to secure real jobs with real futures. Instead of pursuing a track to economic independence and personal fulfillment, millions of people are consigned to a life of low (or no) earnings, poverty and isolation.

According to the Institute for Community Inclusion (ICI) at the University of Massachusetts-Boston, in FY 2003, 26% of individuals with DD worked in integrated jobs including individual and supported employment. ICI found that in FY 2008, 21.9% of individuals receiving day supports from State DD Agencies participated in integrated employment. Unfortunately sheltered or facility based employment has grown steadily during this period,

while the number of individuals working in integrated employment has remained essentially flat since 1999. Regrettably, Employment services for people with intellectual and developmental disabilities still favors facility-based service options.

Councils on Developmental Disabilities seek to change and enhance expectations around employment and to promote progressive changes in the support infrastructure that will enable people with developmental disabilities to pursue employment opportunities and economic independence. Employment First is a service delivery strategy that presumes that all citizens with significant disabilities can and should work in the community. Employment First supports competitive, integrated employment as the preferred outcome and requires that systems have a statutory responsibility to provide services and align their reimbursement practices, policies and guidance to incentivize, encourage and fund services and supports that lead to this preferred outcome.

Employment First provides a policy framework to help individuals with disabilities gain integrated employment. It seeks to remove barriers to employment. These barriers may include transportation and flexible options for on the job support.

The strategy includes the issuance and implementation of policies, practices, and procedures promulgated through federal and state statutes, regulations, and/or operational procedures. All individuals should have the opportunity to pursue a fulfilling employment experience.

Continuing the movement towards person-centered community supports and individualized services

The movement toward individualized services and supports seeks to address the needs of the individual through flexibility in service and service delivery and to empower individuals and families by respecting their personal goals and their right make choices. This process allows families and individuals with developmental disabilities to manage available services. These services and supports are aimed to achieve personal independence, inclusion and employment for individuals with developmental disabilities.

Person-centered thinking is transforming whole systems of care and organizations that serve people with developmental disabilities. DD Councils have for many years been advocates of person-centered decision making for individuals and families. They have been advocating for states to move from systems where fixed dollar amounts are tied to services to a more person centered approach, especially for services located in the community.

It is fitting that the Obama Administration has designated 2010 as the “Year of Community Living”; indeed, many individuals with developmental disabilities now live in the community, either in their family’s home, their own home or in group homes and facilities. Today, States have the ability through Medicaid reimbursement (Home and Community Based Services Waivers) to provide services and supports to people with developmental disabilities in the community, including case management, personal care services, home health aides and transportation. Each state organizes these services differently; however, most are administered by local public and private agencies that contract with providers.

While NACDD and other advocates for full community inclusion applaud the growth of the HCBS waiver, we also acknowledge the rising cost of care for individuals with developmental disabilities which now comprises a large portion of Medicaid spending; As a result, most states do not have the resources to meet demand and already large waiting lists for needed services are growing. Federal leadership and support are essential to protect the beneficiaries of HCBS and other Medicaid services.

Modernizing Council outreach to embrace the use and development of technology for people with disabilities to help bridge the “Digital Divide”

This includes encouraging the use of online social networks where relationships are formed by electronic conversations among people who share a common interest. Online social networks can: spread knowledge quickly; connect persons and create communities over vast distances; rally persons around a cause; and encourage collective thinking and problem-solving.

People with developmental disabilities and their families should be able to participate in the online social networking revolution alongside everyone else. However, a digital divide is growing, with some people enjoying easy access to information and online communications, while others do not. We must fight the “digital divide” and work to ensure that online communications and social networks are disability-accessible and within economic and practical reach of people with developmental disabilities and their families.

We should also encourage the development of other technologies that can help people with disabilities live more independent lives. One such example is the “Smart Home,” several of which have already been built. These state-of-the-art residences can help address the rapidly growing need for optimal long-term care and supports for people with disabilities.¹

Supporting efforts to address the sharp rise of autism diagnoses, and assisting DD advocates, families, service providers, and health systems in meeting the needs of children and adults across the autism spectrum; further engaging people with autism, their families and service providers in the broader DD movement

NACDD and its member Councils work to benefit *all* people with developmental disabilities and their families, and seek programs and policies that benefit people with *all* kinds of developmental disabilities. We prefer policies and programs that benefit the broader community rather than target a specific diagnosis or condition. Yet we acknowledge the alarming growth in the rate of autism diagnoses, and the subsequent increased interest in, concern about, and action on autism.

Indeed, autism is the fastest growing segment of the broader developmental disabilities population. Like all people with developmental disabilities, children and adults on the autism spectrum have the same rights as other people to exert control and choice over their lives, to live independently and to participate fully in, and contribute to, their communities. Like other people with developmental disabilities, people with autism need assistance in early intervention and education, transition from school to work, health, recreation, employment, housing, and transportation. These are the “areas of emphasis” in the DD Act that Councils are charged to address. As such, it is

essential that Councils continue to engage the autism community as a vital part of the broader DD community, and that people with autism, and advocacy organizations that address their needs, work with Councils to build better futures that include economic opportunities, independent living and full participation in community life.

The Next 40 Years

Since 1970, Councils have played a vital role in giving voice to, and addressing the needs of, people with developmental disabilities and their families. Councils provide a literal and figurative “seat at the table” for them.

Today, many people with developmental disabilities and their families benefit from systems that provide services and supports in the community. However, our work is far from complete. Too many children with developmental disabilities remain in segregated classrooms and schools. Many adults with developmental disabilities and their families remain on long waiting lists for services and for community-based housing. We are now witnessing a disturbing reemergence of institutional-style living settings, including a trend towards segregated housing for people with developmental disabilities. Adults with developmental disabilities continue to experience the highest rate of unemployment of any group of Americans. The quality of services and supports for people with developmental disabilities and their families varies widely, and must be improved and ensured.

And so our work continues. We cannot and will not rest until all people with developmental disabilities are able to live lives to their fullest potential, as valued and contributing members of the community. This is our goal and our pledge.

¹ Rizzolo, M.K. & Braddock, D. (2008). People with Cognitive Disabilities. In A. Helal, M. Mokhtari, & B. Abdulrazak (Eds.) The engineering handbook of smart technology for aging, disability, and independence (pp. 203-215). New Jersey: Wiley.

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Braddock, D., Hemp, R., & Rizzolo, M. (2008). The state of the states in developmental disabilities, 2008. Boulder and Washington, DC: University of Colorado School of Medicine, Department of Psychiatry and American Association on Intellectual and Developmental Disabilities.

Council Directory

Alabama

Alabama Council for DD
RSA Union Building
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Montgomery, AL 36130-1410
334-242-3973
www.acdd.org

Alaska

Governor’s Council on
Disabilities and Special Ed.
P.O. Box 240249
Anchorage, AK 99524-0249
907-269-8990
www.hss.state.ak.us/gcdse

American Samoa

American Samoa DD Council
P.O. Box 1455
Pago Pago, American Samoa 96799
684-633-2696

Arizona

Arizona Developmental Disabilities
Planning Council
1740 W. Adams, Suite 201,
Site Code 074Z
Phoenix, Arizona 85007
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www.azgovernor.gov/ddpc

Arkansas

Governor’s DD Council
Freeway Medical Tower
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Little Rock, AR 72204
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www.ddcouncil.org

California

California State Council on DD
1507 21st Street, Suite 210
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www.scdd.ca.gov

Colorado

Colorado DD Council
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Commonwealth of the
Northern Mariana Islands

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Saipan, MP 96950-2565
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Connecticut

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TDD: 860-418-6172
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Delaware

Delaware DD Council
Margaret M. O’Neil Bldg, 2nd Fl
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TDD/Help Line: 800-464-HELP
http://ddc.delaware.gov/

District of Columbia

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TTY: 202-727-3363

Florida

Florida DD Council
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800-580-7801
www.fddc.org

Georgia

Georgia Council on
Developmental Disabilities
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Atlanta, GA 30303
404-657-2126 / TDD: 404-657-2133
www.gcdd.org

Guam

Guam DD Council
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130 University Drive
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www.guamddc.com

Hawaii

Hawaii State Council on DD
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www.hiddc.org

Idaho

Idaho State Council on DD
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700 W. State Street
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208-334-2178 / 800-544-2433
TTY: 208-334-2179
www.icdd.idaho.gov

Illinois

Illinois Council on DD
100 W. Randolph, Suite 10-600
Chicago, IL 60601
312-814-2080
www.state.il.us/agency/icdd

Indiana

Gov’s Council for People
with Disabilities
150 W. Market St., Suite 628
Indianapolis, IN 46204
317-232-7770
www.in.gov/gpcpd/

Iowa

Iowa DD Council
617 East Second Street
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Kansas

Kansas Council on DD
Docking State Office Building
915 S.W. Harrison, Room 141
Topeka, KS 66612-1570
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www.kcdd.org

Kentucky

Kentucky Council on DD
100 Fair Oaks Lane, 4th Floor
Frankfort, KY 40601
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www.kcdd.ky.gov

Louisiana

Louisiana DD Council
647 Main St.
Baton Rouge, LA 70802
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www.laddc.org

Maine

Maine DD Council
139 State House Station
Augusta, ME 04333-0139
207-287-4213
www.maineddc.org

Maryland

Maryland DD Council
217 E. Redwood St., Suite 1300
Baltimore, MD 21202
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www.md-council.org

Massachusetts

Massachusetts DD Council
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Quincy, MA 02169
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www.mass.gov/mddc

Michigan

Michigan DD Council
1033 S. Washington Ave., 3rd Fl
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517-334-7240
www.michigan.gov/mdch

Minnesota

Governor’s Council on DD
370 Centennial Office Building
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651-296-9964
MN Relay Service: 800-627-3529
www.mncdd.org

Mississippi

Mississippi DD Council
239 North Lamar Street
1101 Robert E. Lee Building
Jackson, MS 39201
601-359-6242
TDD: 601-359-6230
www.cdd.ms.gov

Missouri

Missouri Planning Council
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1716 Four Seasons Dr., Suite 103
Jefferson City, MO 65101
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www.mpcdd.com

Montana

Montana Council on DD
2714 Billings Ave
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www.mtcdd.org

Nebraska

Nebraska Planning Council on DD
301 Centennial Mall South
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TDD: 402-471-9570
www.dhhs.ne.gov/ddplanning

Nevada

Governor’s Council on DD
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Carson City, NV 89706
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www.nevadaddcouncil.org

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Developmental Disabilities
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Concord, NH 03301-2451
603-271-3236
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www.nhddc.org

New Jersey

New Jersey Council on DD
20 West State St., P.O. Box 700
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www.njcdd.org

New Mexico

New Mexico DD Planning Council
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www.nmddpc.com

New York

New York State DD Council
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www.ddpc.state.ny.us

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North Carolina Council on DD
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www.nccdd.org

North Dakota

North Dakota State Council on DD
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www.ndscdd.org

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Ohio DD Council
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TDD: 614-644-5530
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Oklahoma

Oklahoma DD Council
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www.okddc.ok.gov

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Oregon Council on DD
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www.paddc.org

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Puerto Rico DD Council
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South Carolina

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Columbia, SC 29201
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www.scdde.state.sc.us

South Dakota

South Dakota Council on DD
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Vermont Developmental
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Wisconsin Board for People with
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**Honoring our Past,
Shaping our Future
Councils on Developmental Disabilities**

NACDD serves as the national voice of State and Territorial Councils on Developmental Disabilities. We support Councils in implementing the Developmental Disabilities Assistance and Bill of Rights Act and promoting the interests and rights of people with developmental disabilities and their families.

www.nacdd.org